Title: The prevalence and general health status of people with co-occurring intellectual disabilities and autism – a total population study.

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Abstract

Background: Little is known about the population prevalence of co-occurring intellectual disabilities and autism, and its impact on general health status. This study aimed to investigate this, in comparison with the general population.

Method: Whole country data from Scotland's Census, 2011 were analysed. Descriptive statistics were generated, χ^2 tests undertaken, and logistic regressions undertaken both with the whole general population data, adjusted for age and gender, and within the population with co-occurring intellectual disabilities and autism.

Results: 5,709/5,295,403 (1.08/1,000) people had co-occurring intellectual disabilities and autism; 2.58/1,000 children/young people and 0.74/1,000 adults. The peak reported prevalence was at age 10 years (3.78/1,000). 66.0% were male. Their general health status was substantially poorer than for the rest of the population, more so for children/young people, and they had more limitations in their day-to-day activities. Co-occurring intellectual disabilities and autism had odds ratio=48.8 (45.0-53.0) in statistically predicting poor health.

Conclusion: This is the first study to report the population prevalence of co-existing intellectual disabilities and autism, and the substantial influence this double-disadvantage has on general health status, apparent across the entire life-course. This highlights a group in need of wider recognition for whom resources should be focused on and planned for, informed by evidence. Staff in services for people with either of these conditions need to be trained, equipped, resourced and prepared to address the challenge of working for people with this duality. This is essential, to address these substantial health inequalities.

Key words: intellectual disabilities, autism, general health, prevalence, health inequalities

Background

Intellectual disabilities and autism often co-occur, and both are life-long conditions so require long-term support from services for educational, health, and social care needs. Despite this, we have been unable to find reports on the population prevalence of co-occurring intellectual disabilities and autism, nor on the general health status of people with these co-occurring conditions. Studies have tended to focus on the prevalence of intellectual disabilities in people with autism, or the prevalence of autism in people with intellectual disabilities, but not on the population prevalence of co-occurrence of both conditions which is the important metric for service planning.

Indeed, even the population prevalence of the single conditions of intellectual disabilities and of autism is contentious. A recent systematic review of prevalence studies reported an adult rate of intellectual disabilities of 4.94/1,000, an adult and child/youth combined rate of 5.04/1,000, and for children only of 18.30/1,000 (Maulik et al, 2011). The review was not able to report rates for specific age groups further due to the limitations of the information provided in the synthesised studies. Additionally, the included studies were highly variable in methodology, size, quality, and representativeness of the studies; and geography and time (cohort effects) can affect prevalence of intellectual disabilities (Cooper et al, 2016). Several systematic reviews have attempted to synthesise studies on prevalence of autism. Individual studies vary markedly, dependent upon age-ranges, when the studies were conducted (and hence the diagnostic criteria used, given that these have been broadened out in recent years), data-collection methods, size, quality, and representativeness of included studies. Hence synthesized rates also vary, depending upon the studies included: even when restricted to studies published since 2000, reported overall synthesised prevalence rates vary considerably. For example, for autistic disorder: median prevalence of 2.2/1,000 (French et al, 2013); European median prevalence of 1.9/1,000 (Elsabbagh et al. 2012); median prevalence of 2.8/1,000 (Tsai, 2014); whilst for pervasive developmental disorders: median prevalence of 6.2/1,000 (Elsabbagh et al. 2012); and 7.0/1,000 (with wide range) (Tsai, 2014). Notably, these studies were exclusively restricted to children, young people and young adults.

Studies on the prevalence of autism in people with intellectual disabilities have varied considerably in their findings, for the same reasons described above, particularly the criteria used and sampling methods. A systematic review found 4.5%-25.1% of children with intellectual disabilities were reported to have

autistic disorder (Oeseburg et al, 2011), with higher rates the more severe the child's intellectual disabilities. A systematic review of adults with intellectual disabilities reported prevalence of autism of 8%-30% (Emerson and Baines, 2010), with prevalence higher the more severe the intellectual disabilities. A more recent study reported autism in 1.0% of adults with mild/borderline intellectual disabilities and 39.3% in adults with moderate-profound intellectual disabilities (Brugha et al, 2016). Conversely, studies have estimated the prevalence of intellectual disabilities among people with autism. These also vary in their findings: a range of 15%-84% has been reported (Emerson & Baines, 2010). Reviews of older studies (1996-2001) (albeit with small samples, and variable sampling and methodology) found intellectual disabilities to occur in an estimated 50-70% of people with autism (Fombonne, 2003). However, change in reported prevalence of autism has occurred over time, in view of the broadening criteria for the autism spectrum; as reported prevalence of autism has increased, the proportion identified with intellectual disabilities has fallen. For example, records of 8 year old children in Atlanta, USA, showed the proportion with autism who also had intellectual disabilities recorded fell from 59% to 37% from 1996 to 2010 (whilst recorded rates of autism rose) (Van Naarden Braun et al., 2015). In adults, a recent study in North California, USA, used medical records to identify 1,507/1,578,658 (0.1%) adults with autism, and found that 19.2% also had a record of intellectual disabilities (Croen et al, 2015). The study does, however, reflect the sampling frame; only those individuals with an existing record of autism in their medical records were identified as having autism.

In summary, whilst there are studies on the prevalence of intellectual disabilities, and the prevalence of autism, we have been unable to identify studies on the population prevalence of co-occurring intellectual disabilities and autism. Studies that have reported the prevalence of autism in people with intellectual disabilities, or intellectual disabilities in people with autism, have mostly focussed just on children and young people, and systematic reviews are difficult to interpret due to the changing (widening) criteria for the autism spectrum over time, which invalidates some review findings from this perspective.

Our understanding of the general health status of people with co-occurring intellectual disabilities and autism is very limited. Ratings of general health are important as they are associated with morbidity and mortality in the general population (Mewton & Andrews, 2013; Young et al, 2010). General health status has been reported to be considerably poorer for people with intellectual disabilities of all ages compared with the general population (Haider et al,

2013; Emerson et al, 2016; Hughes-McCormack et al, 2017). A large, representative study of a whole population found that the odds ratio of intellectual disabilities in predicting poor general health status was as high as 9.2, or 43.2 when the interaction term age x intellectual disabilities was taken into account (Hughes-McCormack, et al, 2017). It may well be poorer still for people with intellectual disabilities who also have co-occurring autism, however, we were unable to identify any previous studies that have quantified this. This is a serious gap in the literature; studies to date suggest that although not yet quantified, co-occurring intellectual disabilities and autism is certainly not uncommon, and if this doubly-disadvantaged population does indeed also have poorer general health, then it would highlight a group in need of wider recognition for whom resources should be focused on and planned for, informed by evidence.

This paper aims to investigate the population prevalence of co-occurring intellectual disabilities and autism, and the general health status of children, young people, and adults with co-occurring intellectual disabilities and autism compared with the general population.

Methods

Data Source

Scotland's Census is the official estimate of every person and household in the country. The census takes place every 10 years and was last conducted on 27th March 2011. Scotland's Census, 2011 required a member of each household to complete the census information about the household and all members of the household, and each manager of communal establishments to complete information about the establishment and all its residents. Help was available from the Census team if needed. The Census informed households that failure to make a Census return, or supplying false information could result in a £1,000 fine. Non-responses were followed up by the Census team. These factors resulted in a very high response rate, with an estimated coverage of 94% of all of Scotland's population. The Census team also used a Census Coverage Survey with about 40,000 households, to estimate numbers and characteristics of the missing 6%. The Coverage Survey and Census records were deterministically matched to check for duplicates. Individuals estimated to have been missed were then imputed using a subset of characteristics from real individuals. The edit and imputation methodology was adapted from the

Office for National Statistics rigorous and systematic guidelines. Further detail is available at: http://www.scotlandscensus.gov.uk/documents/censusresults/release1b/rel1bmethodology.pdf

Given the method of data collection employed by the Census, and the reading age required for the questions and responses, we consider it unlikely that people with co-occurring intellectual disabilities and autism completed the form, and rather, that the people who did so were parent-carers in family households, support workers for people living in supported accommodation, and the managers/key workers at communal establishments.

More information on the census can be obtained from the National Records of Scotland website: http://www.scotlandscensus.gov.uk/.

Variables

Intellectual Disabilities and Autism

People with co-occurring intellectual disabilities and autism were identified by the census question: 'Do you have any of the following conditions which have lasted, or are expected to last, at least 12 months? Tick all that apply'. There was a choice of ten possible responses to this question: deafness or partial hearing loss; blindness or partial sight loss; learning disability (for example, Downs Syndrome); learning difficulty (for example, dyslexia); developmental disorder (for example, Autistic Spectrum Disorder or Asperger's Syndrome); physical disability; mental health condition; long-term illness, disease or condition; other condition. For 'other condition' the option of providing more detail in an open response was provided.

In Scotland, the term "learning disability" is used synonymously with that of "intellectual disabilities" used internationally. Importantly, the Census differentiated between intellectual disabilities and specific learning disabilities; and between intellectual disabilities and autism.

During the methodology development for Scotland's Census, 2011, Ipsos MORI Scotland was commissioned to undertake cognitive question testing on the questions on long-term health conditions and disabilities. This was to test whether the questions were answered accurately and willingly, and to identify any changes needed to improve data quality and/or the acceptability. Cognitive interviewing is a widely used approach to critically evaluate and improve survey

questionnaires (Wills, 2005). It enables researchers to modify survey material to enhance clarity. Retrospective probing was selected as the most appropriate technique, conducted with 102 participants with a mix of gender, age and health conditions and disabilities (including people with more than one of the conditions). They included people with autism, intellectual disabilities, dyslexia, dyspraxia, speech impairment, mental health conditions (both milder and more serious), and other long-term conditions. This resulted in a redesign of the question on autism, to 'Developmental disorder, for example autism spectrum disorder or Asperger's syndrome' in order to accurately capture specifically the data on autism. The questions on the other conditions tested (some of which, from a medical perspective, can be considered as developmental disorders) did not require any modification.

Hence the choice of wording of the question on autism was informed and carefully considered. The term developmental disorder was used and only prompted respondents to reply with regards to autistic spectrum disorder or Asperger's syndrome, and the question distinguished autism from learning disability, learning difficulties such as dyslexia, and mental health conditions.

The Census team imputed answers for the 14.7% who did not tick any of the boxes in question on long-term conditions, based on their free text answers for this question and answers to other health questions in the Census, which increased the completion rate to 97.4%. For the remaining 2.6%, the Census team assumed the most plausible explanation was that the person had no long-term condition but did not see the "No condition" check box at the end of the question, and hence recorded them as such.

General Health

General health was measured by the response to the question: 'How is your health in general?' There was a choice of five possible responses to this question: very good, good, fair, bad, and very bad.

Limitation in Day-to-Day Activities

The effect of health on daily activities was measured by the question: 'Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, as least 12 months?' There was a choice of three possible responses to this question: 'yes, limited a lot', 'yes, limited a little', 'no'.

Procedure

Approval to access data from the Scotland Census, 2011 was obtained from the Scottish Government. Data was then downloaded from the NRS Census data archive.

Data Analysis

We calculated the number and rate per 1,000 population of children/young people and of adults having co-occurring intellectual disabilities and autism. We calculated the number and percentage of people with co-occurring intellectual disabilities and autism by gender, age, country of birth, and ethnicity, and drew comparison with the rest of the population using chi-squared (χ^2) tests. We calculated the number and percentage of people with co-occurring intellectual disabilities and autism who reported very good, good, fair, bad, and very bad health; and how limited their day-to-day activities were because of a health problem or disability, and drew comparison with the rest of the population, using χ^2 tests. We then used logistic regression in the whole population to calculate the odds ratio (OR: 95% confidence interval, 95% CI) of co-occurring intellectual disabilities and autism in statistically predicting a derived, dichotomised dependent variable of poor health (fair, bad, or very bad health) compared to good health (good or very good health), adjusting for age and gender. Gender was binary, with male as the reference group. Age was categorised into groups: 0-15, 16-24, 25-34, 35-44, 45-54, 55-64, 65-74, 75+, with 0-15 years as the reference group. We then repeated the regression within the whole population, adding the interaction term age x co-occurring intellectual disabilities and autism. Additionally, we then used logistic regression within the population with co-occurring intellectual disabilities and autism to determine the OR (95% CI) of gender and age group in predicting the derived dependent variable of poor health. The same reference groups were used. All analysis was conducted using SPSS software version 22.

Results

Prevalence and characteristics

Scotland's Census, 2011, includes records on 5,295,403 people aged 0-75+ years. 5,709/5,295,403 (1.08/1,000) people had co-occurring intellectual disabilities and autism; of whom 3,769 (66.0%) were male and 1,940 (44.0%) were female. Of the total population, 2,362/916,331 (2.58/1,000) children (0-15 years), and 3,347/4,379,072 (0.74/1,000) adults (16-75+ years) had co-occurring intellectual disabilities and autism. Of the children, the peak

reported prevalence was at age 10 years, with 208/55,067 (3.78/1,000) children age 10 having co-occurring intellectual disabilities and autism.

Compared with the rest of the population, the population with co-occurring intellectual disabilities and autism were more male (66.0% versus 48.5%; χ^2=703.5; df=1; p<0.001); younger (χ^2=3894.7; df=7; p<0.001); more likely to have been born in the UK rather than elsewhere (χ^2=101.9; df=1; p<0.001), revealing lesser geographic mobility; but no different with regards to Caucasian versus non-Caucasian ethnicity (χ^2=1.1; df=1; p=0.3) (table 1).

Of the Scottish population with intellectual disabilities, 21.7% had autism, and of the Scottish population with autism 18.0% had intellectual disabilities.

- Insert table 1 about here -

General health and limitations in daily activities

People with co-occurring intellectual disabilities and autism had poorer general health status, compared with the rest of the population (table 2). This difference was apparent at all ages, most markedly so in childhood and youth. Very good or good general health was reported for only 47.7% of children/young people with co-occurring intellectual disabilities and autism compared with 96.2% of the rest of the population, 52.4% compared with 85.5% at ages 16-64, and 45.5% compared with 54.4% at age 65+ years (table 2).

People with co-occurring intellectual disabilities and autism also had more limitations in day-to-day activities because of a health problem or disability, compared with the rest of the population (table 3). This difference was apparent at all ages, most markedly so in childhood and youth. No limitations at all were reported for only 5.6% of children/young people with co-occurring intellectual disabilities and autism compared with 95.4% of the rest of the population, 10.9% compared with 85.1% at ages 16-64, and 28.3% compared with 46.8% at age 65+ years (table 3).

- Insert tables 2 and 3 about here -

Adjusting for age and gender, given the different distributions in the two populations, having co-occurring intellectual disabilities and autism had an odds ratio=18.5 (17.5-19.6, 95% CI) in predicting poor health (table 4). Health was progressively poorer for each older age group, and females were marginally more likely than males to have poor health. When the interaction term was added (age x co-occurring intellectual disabilities and autism), co-

occurring intellectual disabilities and autism had an OR=48.8 (45.0-53.0) in predicting poor health (table 4). Within the population with co-occurring intellectual disabilities and autism, older age group had much less influence than that seen within the whole general population.

Within the population with co-occurring intellectual disabilities and autism, the OR =1.295 (1.160, 1.446 95% CI) of female gender predicted the derived poor health. Age group did not predict poor health, other than it being better for the 16-24 year age group than in children, with the suggestion of a gradient thereafter, but not of statistical significance (table 5).

- Insert tables 4 and 5 about here -

Discussion

We believe this is this is the first study to report the population prevalence of co-existing intellectual disabilities and autism, and the general health status of this doubly-disadvantaged group compared with the rest of the population. The population prevalence is 1.08/1,000. This population is younger than the general population, with a higher prevalence in childhood than in adulthood, and the majority are male. They have substantially poorer general health than the general population, being 19 times more likely to have poorer health, or 49 times when the interaction with age is taken into account. The great majority also had more limitations in their day-to-day activities. These inequalities are across the whole of the lifecourse, and indeed were greatest in childhood/youth. Whilst in the general population health becomes poorer with age, this was not the case in the population with co-occurring intellectual disabilities and autism, likely reflecting the earlier death of people with more severe intellectual disabilities (O'Leary et al, 2017), who are the group most likely to have autism, and who also have more health morbidity and multi-morbidity (Kinnear et al, 2018). Females had poorer health than males, and more so than the slight gender inequity seen in the general population. Of the Scottish population with intellectual disabilities, 21.7% had autism, and of the Scottish population with autism, 18.0% had intellectual disabilities.

These findings are important. Clearly, given their poor health and limitations in day-to-day activities, people with co-occurring intellectual disabilities and autism need the right level and types of health and social supports. Services designed for people with autism may not be equipped to fully address the needs of people who also have intellectual disabilities, and vice versa. We need

to better understand their specific health profile, and differences and similarities with people who live with just one of these life-long conditions. We have previously studied people with intellectual disabilities and found intellectual disabilities to impact upon general health status to a large extent (Hughes-McCormack et al, 2017), but less so than for this population with both intellectual disabilities and autism. We hope the findings from our study will heighten the awareness of practitioners to this issue.

We are not aware of other studies of general health status of people with co-occurring intellectual disabilities and autism with which we can compare these results.

Strengths of the study include its large scale, the very high response rate in Scotland's Census, 2011 (94%), and that intellectual disabilities, autism, and general health status were enquired about systematically for everyone in the population. The cognitive question testing during the design of the Census questions is a further strength. The data collection was recent (2011), so relevant now, which is important given the broadening out of criteria for the autism spectrum. The Census covered the entire population of the country and so is representative, and results can be generalised to other high income countries. Limitations include the proxy-reporting by one person per household, which may, or may not reflect self-reports (we consider it unlikely that the people with co-occurring intellectual disabilities and autism self-reported their general health status). Without proxy-reports, we would have no information on people unable to self-report due to their disabilities, and a previous review on the topic concluded that overall, proxy reports are a useful addition to determine aspects of well-being in people with intellectual disabilities (Perkins, 2007). Additionally, people were reported who were known to have autism/Asperger's syndrome rather than undergoing detailed research assessments which are clearly not possible in such large population studies, and may therefore be subject to a degree of error which we were not able to check.

We found that co-occurring intellectual disabilities and autism are not at all uncommon, and hence staff in services for people with either of these conditions need to be trained, equipped, resourced and prepared to address the challenge of working for people with this duality. This is essential, to address the substantial health inequalities that we have reported to currently exist.

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Table 1: Characteristics of people with, and without, co-occurring intellectual disabilities and autism

	Without co-occurring intellectual disabilities and autism N=5,289,694 (100%) Number (%)	**Co-occurring intellectual disabilities and autism** N=5,709 (100%) Number (%)
Gender*		
Males	2,563,675 (48.5%)	3,769 (66.0%)
Females	2,726,019 (51.5%)	1,940 (44.0%)
Age groups*		
0-15	913,969 (17.3%)	2,362 (19.9%)
16-24	631,094 (11.9%)	1,394 (15.8%)
25-34	666,725 (12.6%)	602(13.2%)
35-44	734,304 (13.9%)	450 (14.6%)
45-54	786,355 (14.9%)	401 (16.3%)
55-64	667,157 (12.6%)	256 (10.9%)
65+	890,090 (16.8%)	244 (4.3%)
Country of birth*		
UK	4,920,614 (93.0%)	5,505 (96.4%)
Other Europe	172,160 (3.3%)	83 (1.5%)
Africa	46,708 (0.9%)	34 (0.6%)
Middle East and Asia	104,480 (2.0%)	50 (0.9%)
The Americas and the Caribbean	33,325 (0.6%)	28 (0.5%)
Other	12,407 (0.2%)	9 (0.2%)
Ethnicity		
White	5,078,910 (96.0%)	5,497 (96.3%)
Asian	140,542 (2.7%)	136 (2.4%)

Mixed/multiple ethnicities	19,775 (0.4%)	40 (0.7%)
African	29,615 (0.6%)	23 (0.4%)
Caribbean or black	6,536 (0.1%)	4 (0.1%)
Other ethnic groups	14,316 (0.3%)	9 (0.2%)

*People with co-occurring intellectual disabilities and autism versus the rest of the population; $p<0.01$

Table 2: General health of people with, and without, co-occurring intellectual disabilities and autism

General health	**Children/youth, 0-15 years**			**Adults, 16-64 years**			**Older people, 65+ years**		
	Without co-occurring intellectual disabilities and autism N=913,969 (100%)	Co-occurring intellectual disabilities and autism N=2,362 (100%)	p-value	Without co-occurring intellectual disabilities and autism N=3,459,515 (100%)	Co-occurring intellectual disabilities and autism N=3,103 (100%)	p-value	Without co-occurring intellectual disabilities and autism N=887,425 (100%)	Co-occurring intellectual disabilities and autism N=244 (100%)	p-value
Very good	757,710 (82.9%)	418 (17.7%)	P<0.001	1,852,724 (53.6%)	568 (18.3%)	P<0.001	153,191 (17.3%)	34 (13.9%)	P<0.001
Good	121,837 (13.3%)	709 (30.0%)		1,105,174 (31.9%)	1,057 (34.1%)		329,658 (37.1%)	77 (31.6%)	
Fair	13,837 (1.5%)	805 (34.1%)		334,402 (9.7%)	948 (30.6%)		283,261 (31.9%)	91 (37.3%)	
Bad	2,124 (0.2%)	254 (10.8%)		128,103 (3.7%)	330 (10.6%)		91,949 (10.4%)	25 (10.2%)	
Very bad	603 (0.1%)	176 (7.5%)		39,112 (1.1%)	200 (6.4%)		29,366 (3.3%)	17 (7.0%)	

Table 3: Limitation of day-to-day activities of people with, and without, co-occurring intellectual disabilities and autism

Limitation of day-to-day activities	**Children/youth, 0-15 years**			**Adults, 16-64 years**			**Older people, 65+ years**		
	Without co-occurring intellectual disabilities and autism N=913,969 (100%)	Co-occurring intellectual disabilities and autism N=2,362 (100%)	p-value	Without co-occurring intellectual disabilities and autism N=3,485,635 (100%)	Co-occurring intellectual disabilities and autism N=3,103 (100%)	p-value	Without co-occurring intellectual disabilities and autism N=890,090 (100%)	Co-occurring intellectual disabilities and autism N=244 (100%)	p-value
Limited a lot	13,655 (1.5%)	1,829 (77.4%)	P<0.001	242,198 (6.9%)	2,229 (71.8%)	P<0.001	245,839 (27.7%)	113 (46.3%)	P<0.001
Limited a little	28,059 (3.1%)	400 (16.9%)		277,959 (8.0%)	537 (17.3%)		227,491 (25.6%)	62 (25.4%)	
Not limited	872,255 (95.4%)	133 (5.6%)		2,965,478 (85.1%)	337 (10.9%)		416,760 (46.8%)	69 (28.3%)	

Table 4: Independent predictors of poor health in the whole population

Characteristic		**Regression 1**		**Regression 2 (including the interaction term: age x co-occurring intellectual disabilities and autism)**	
		Odds ratio	**95% confidence interval**	**Odds ratio**	**95% confidence interval**
Co-occurring intellectual disabilities and autism	Not present (reference)	-	-	-	-
	Co-occurring intellectual disabilities and autism	18.539	17.499-19.640	48.796	44.958, 52.962
Gender	Male (reference)	-	-	-	-
	Female	1.022	1.017-1.027	1.022	1.017, 1.027
Age	0-15 (reference)	-	-	-	-
	16-24	2.069	2.032-2.106	2.125	2.087, 2.164
	25-34	3.598	3.539-3.657	3.699	3.638, 3.761
	35-44	6.377	6.281-6.475	6.555	6.455, 6.657
	45-54	12.106	11.929-12.286	12.441	12.255, 12.629
	55-64	17.168	16.919-17.420	17.633	17.373, 17.897
	65+	36.593	36.076-37.118	37.578	37.037, 38.123
Age x co-occurring intellectual disabilities and autism	0-15 (reference)	-	-	-	-
	16-24	-	-	0.358	0.313, 0.409
	25-34	-	-	0.228	0.190, 0.273

	35-44	-	-	0.128	0.105, 0.157
	45-54	-	-	0.076	0.061, 0.094
	55-64	-	-	0.058	0.045, 0.075
	65+	-	-	0.029	0.022, 0.038
Constant	-	0.023	-	.022	-

Table 5: Independent predictors of poor health within the population with co-occurring intellectual disabilities and autism

Characteristic		**Odds ratio**	**95% confidence interval**
Gender	Male (reference)	-	-
	Female	1.295	1.160-1.446
Age	0-15 (reference)	-	-
	16-24	0.765	0.669-0.873
	25-34	0.839	0.701-1.004
	35-44	0.845	0.690-1.034
	45-54	0.946	0.765-1.170
	55-64	1.007	0.777-1.304
	65+	1.061	0.814-1.384
	Constant	1.005	-